

The Decision to Continue: The Experiences and Needs of Parents who Receive a Prenatal Diagnosis of Holoprosencephaly

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Holoprosencephaly (HPE) is a condition characterized by a defect in the development of the midline embryonic forebrain. When detected prenatally, the diagnosis of HPE offers parents a poor but often uncertain prognosis. Since the majority of parents receiving prenatal diagnosis of an abnormality terminate their pregnancies, few studies have examined parents' experiences and needs surrounding the decision to continue a pregnancy.

We present a descriptive study of in-depth interviews with twenty-four parents who chose to continue their pregnancy after receiving a prenatal diagnosis of HPE. Parents were asked about their decision-making process to continue the pregnancy. Qualitative analysis was used to identify common themes that emerged from these parents' experiences.

The results suggest that most parents did not make an active decision about continuing the pregnancy. Rather, they described a more subtle decision-making process that evolved over time and consisted of several factors. These factors included the parents' religious and personal beliefs, past experiences, and the uncertainty involved in the diagnosis of HPE. Throughout the decision-making process, they described informational, emotional, and supportive needs from family, friends, and health professionals. All of these factors contributed to the evolution of the parents' decision to continue the pregnancy and the acceptance of their decision.

Results of this exploratory study suggest health care professionals, specifically genetic counselors, need to work with parents as they make their decision to continue an affected pregnancy and as the pregnancy continues. The results also provide the groundwork for prospective investigation into parents' decision-making process as they receive and adjust to prenatal diagnoses of an abnormality.

Reference:

Redlinger-Grosse, K., Bernhardt, B.A., Berg, K., Muenke, M., Biesecker, B.B.
The decision to continue: The experiences and needs of parents who receive a prenatal diagnosis of Holoprosencephaly. *American Journal of Medical Genetics*. (in press).